DRAFT
MEETING MINUTES
Rhode Island All Payer Claims Database
Data Release Review Board Meeting
Friday, May 20th 11:00 am – 12:00 pm
Room 401, RI Department of Health
3 Capitol Hill, Providence, RI 02908

Members Present:
Solmaz Behtash
Michael Lichtenstein
Kimberly Paull
Lawrence Rothstein
Betsy Stubblefield-Loucks
Amy Black
Ira Wilson

Members Absent:
Monica Neronha
Kenny Alston
Patrick Tigue
Cory King

Staff Present:
Nicole Alexander-Scott, Director, Department of Health
Alyssa Ursillo, Freedman HealthCare
Samara Viner-Brown, Department of Health
Melissa Lauer, Executive Office of Health and Human Services

Members of Public Present:
Amanda Barry, Hospital Association of Rhode Island

1. Welcome and Roll Call

The meeting was convened at 11:05 by Board Chair Michael Lichtenstein. Alyssa Ursillo announced that there is a new annual meeting schedule that was sent out and posted. The Board will typically meet from 9 – 11 am on the fourth Friday of each month, with a few exceptions noted in the schedule.

2. Discuss DRB processes for reviewing applications and making recommendations

Ms. Ursillo discussed the Board procedures for reviewing data request applications for Level 3 extracts. She began by reviewing the recommendation the Board made during the previous meeting, around contracted party's data privacy and security documentation. The Board had recommended that submission of third party documents be optional with the application, but the Board can request further documentation from the applicant at any time. The Director of the Department of Health (DOH), Dr. Alexander-Scott, approved this recommendation.

Dr. Ira Wilson asked for an example of a situation in which a third party would have access to the data, and if this should be discouraged to protect patient privacy. Ms. Ursillo clarified that the Data Use Agreement is between the applicant and DOH, but that any subcontractors will be subject to the same requirements as the applicant. Michael Lichtenstein pointed out that Patrick Tigue had noted during the previous meeting that insurers often have contracted entities that perform data analytics for them. Dr. Wilson agreed that this would be an appropriate case for a third party contract.

Ms. Ursillo informed the Board that the Level 3 data request application has been updated based on the feedback from the previous meeting, and that the updated copy and link to the online version were distributed for Board members to review individually. Mr. Lichtenstein asked if there is a way to save the application and come back later. Ms. Ursillo will check to see if this feature is available, and agreed it was important. She also noted that there is a file size upload limitation for attachments, but that is should be sufficient for the purposes of the application. The online application contains instructions to users about file size and format limitations. Dr. Alexander-Scott suggested that the application contain an email that applicants could use to send files in the event they are too large for the application. Dr. Wilson suggested the staff add an introduction to the application informing applicants that the purpose of the Board review is to protect patient privacy, and that this is not a scientific review.

Ms. Ursillo reviewed the application process, beginning with the role of the APCD staff. When the application is submitted and payment is received, the staff will do a first round of review to make sure the application is complete, the request is for data available in the APCD, and the responses answer the questions asked. If there are any issues with the application, the staff will inform the applicant that they need to address the errors and resubmit, or withdraw their application. Once this is complete, the application will be posted to the APCD website for 10 business days for public comment. The applicant's direct contact information and the data security plan will not be posted for security reasons. The application will then go to the Board at the meeting directly following the end of the public comment period.

Mr. Lichtenstein asked if the 10 day comment period was a minimum comment period. Ms. Ursillo clarified that the Regulations specify it is a minimum comment period, so comments can continue to come in until a few days before the Board meeting. Once the application is processed, the staff will contact the applicant and inform them of the date of the Board meeting during which their application will be reviewed.

The APCD staff will also help to interpret any technical components in the application, such as security plan requirements. Dr. Wilson mentioned that there are different levels of security protocols and asked what kind of qualifications staff have that can help support this review. For example, some basic security measures are that data cannot be taken home, should never be stored on a memory stick or mobile device, etc. He suggested providing applicants with a description of what kind of security measures the Board will be looking for in the data security plan as guidance. Mr. Lichtenstein and Dr. Wilson suggested that this be provided to the Board during the next meeting for review.

Ms. Ursillo reiterated the role of the Board in reviewing applications, which is to ensure:

- Appropriate privacy and security protections are in place to protect patient privacy
- Applicant will adhere to cell size suppression policy
- Access to data is necessary to achieve project's intended goals
- Applicant is qualified to protect and responsibly handle data

Dr. Wilson questioned whether assessing if access to the data is necessary to achieve the project's goals is the role of the Board, as this is a scientific review. Ms. Ursillo clarified that this is to determine if the request is for data beyond the need of their project or not relevant to their project. Dr. Alexander-Scott noted that the key word here is "access to the data" and gave the example that if a project is on lead levels in water, they would not need access to APCD data. Amy Black noted that this aspect of review looks at whether or not the Board can see an obvious link between the project and the data, or whether it's unclear as to why this data would be necessary. The Board agreed that there should be a short description clarifying what this part of the review means.

The Board again discussed whether applicants would attend meetings when their application was being reviewed. Ms. Ursillo clarified that applicants can call-in to the meeting if the Board has conference call capabilities. Calling in would only be an option for the public, as Board members cannot participate telephonically. Dr. Wilson suggested the staff ask the applicant to please come, especially early on while the Board is gaining experience reviewing applications. Dr. Alexander-Scott noted that during a previous meeting, the Board had agreed the applicant would be encouraged to attend but not required. Ms. Black emphasized that the language would need to be carefully worded so that applicants understand they will not penalized if they do not attend the meeting. Mr. Lichtenstein noted that if the Board has a lot of questions and the applicant is not there to respond, it will delay the final recommendation until the Board can get responses. The Board agreed that applicants would be encouraged to attend and could call-in if they are unable to attend in-person. Board members agreed they could not try to attend the meeting via phone.

Ms. Ursillo discussed the voting process for making recommendations. The Board Chair leading the meeting will facilitate the voting process. They will make an initial motion to vote, ask for a second motion, and then solicit each Board member for their vote. The public comment period will be before the vote so that members may consider public comments. There must be a quorum to vote, which is a simple majority of six members. The majority vote will determine the recommendation, but both majority and dissenting opinion will be submitted in the recommendation to the Director for final review and decision. Mr. Lichtenstein asked what happens in the case of a split vote. The Board and Dr. Alexander-Scott agreed that with a split vote, the Director will make the decision once the Board has completed the review and gone through all necessary steps to make a recommendation.

There was a discussion around how to review the data privacy and security plan during a public meeting, as some of the documentation may be proprietary or should not be made public. This may require an executive session. Ms. Ursillo will get clarification as to when a public body can go into executive session.

Ms. Ursillo reviewed the options for making a recommendation:
- Recommend for approval
- Recommend for approval if certain conditions are met
- Not recommended – return with list of deficiencies, revised application is reviewed at a future meeting.

Once the Board makes a recommendation, the Chair will send the written recommendation to the Director. The Director will review and make a decision, which will be shared at the next meeting.

The APCD staff will handle communication with applicant once a decision is made. If approval is contingent upon meeting certain conditions, the staff will ensure those conditions are met. If the request is not recommended for approval, the staff will send a list of deficiencies to the applicant to address and resubmit the application if they choose.

Dr. Wilson mentioned that the case in which someone requests to send personal identifiers to the Lockbox vendor in order to flag a cohort of individuals for research has not been discussed. He thinks this will be a high demand request, and that the Board should consider, timing, efficiency, cost of this type of request and how it affects the review process. Ms. Ursillo indicated that the APCD staff are still reviewing how that will work and that this process will require close review by the RI legal team. This is something that will be explored in the future.

Ms. Ursillo will write up the business rules for reviewing data requests for approval during the next Board meeting.

3. Update on Level 2 file options and impact of cell suppression

Ms. Ursillo provided an update to the Board on where the staff is with developing Level 2 files. She reviewed the recommendation the Board made during the April meeting, which was to continue with cell suppression and explore further combinations of data elements that are meaningful and in which cell suppression is minimal. The Board had also suggested vetting these proposed data sets with a user group. Dr. Alexander-Scott reviewed and approved this recommendation.

Ms. Ursillo reviewed the proposed Level 2 approach, which provides users with two options:
*   Choose from suggested data element combinations that have been pre-determined to be meaningful and have minimal cell suppression, or
*   If the suggested combinations of elements don't meet the user's needs, they may select their own combination of data elements from the list of available elements. The team will notify the user up front as to the impact of cell suppression before the user pays for the file.

Ms. Ursillo provided the Board with information on the HealthFacts RI user webinar on June 8th. The purpose of the webinar will be to explain the State's data release model, and solicit feedback on the Level 2 data set approach. The Board members have been invited to this and can share the webinar info with others in their network that they think will be interested. Mr. Lichtenstein asked if Board members can participate, as this will be telephonic communication. Ms. Ursillo clarified that it is not a Board meeting, and that they can participate as members of the public/on behalf of their agency. Ms. Black noted that another Board she was on had a similar situation and it was okay for members to participate, as they are not participating in their role as a Board member. Ms. Ursillo will update the Board with the discussion from the user group during the next meeting.

4. Public comment

There were no public comments.

5. Next Steps and Adjourn

The Board will approve the business rules and review any applications received at the next meeting. The staff hopes to post applications by the end of June, depending on the progress with extract production. The June Board meeting may be canceled if there are no applications to review at that point.